

Feasibility of Enrollment and Tracking of Longitudinal Outcomes Following TBI: A VA TBI Model System Study

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Background: The Institute of Medicine has determined that TBI is associated with many chronic health conditions and disability. During this time of our nation's longest war and the advances in medical science have allowed for enhanced survival of war-time injuries. Increased need for understanding of longitudinal outcomes to meet the lifetime needs of veterans and service members is growing. In 2009, the Veterans Affairs Rehabilitation Program Office developed an inter-agency agreement with the U.S. Department of Education's National Institute on Disability and Rehabilitation and Research (NIDRR) TBI Model System Program to manage a database of rehabilitation outcome variables. The TBIMS is a longitudinal multi-center study which examines the course of recovery and outcomes following the delivery of a coordinated system of acute neurotrauma and inpatient rehabilitation. The objective of this paper is to provide feasibility and preliminary findings of the VA-TBIMS to date. **Methods:** Participants were enrolled during inpatient Polytrauma Rehabilitation Center hospitalization. Subject characteristics (demographic, preinjury functioning), injury severity (Glasgow Coma Scale (GCS), Post-traumatic Amnesia (PTA) duration, Imaging), and acute hospital course were captured through medical record abstraction, interview, and prospective monitoring during rehabilitation hospitalization. Follow-up study measures were completed at 1, 2, 5 and every 5 years thereafter based on time elapsed since injury. Follow-up measures were administered by telephone, mail-survey, electronic medical record review and included physical, psychological, community reintegration, and global rehabilitation outcomes that overlap with many NINDS Common Data Elements. **Results:** From 2009 through 10/2014, N=627 veterans and service members with TBI were enrolled with an 88% retention rate to date. Study sample is primarily male (96%), young (Median age 28 years), and represent the full TBI severity spectrum (42%= mild, 11% = moderate, = 47% = severe). For those acutely hospitalized, median emergency department or first available GCS score was 9. Duration of PTA was a median of 12.5 days. Sixty percent were deployed in a combat zone at time of injury. Causes of injury included vehicular-related (44%), blast exposure (28%), falls (11%), mixed/other (11%), and penetrating injury

(5%). Outside of VA, medical care was received in many locations both within and across subjects including civilian settings (66%), state-side military (36%), and overseas/Landstuhl, Germany (36%) increasing the challenge of data abstraction of injury severity, comorbidities, and acute hospital recovery course. Common discharge dispositions included private residence (52%), adult home (28%), and hospital settings (13%) across the U.S. thus necessitating telephone and mail follow-up procedures. **Conclusions:** The VA TBIMS has successfully enrolled a large cohort of military-related TBI with successful follow-up rates allowing for injury characterization and improved knowledge of rehabilitation outcome. The infrastructure of the VA-TBIMS was utilized in two successful grant funded-projects (VA HSRD: Veterans with mTBI: Barriers to Community Reintegration; DVBIC: Improved Understanding of Medical And Psychological Needs [I-MAP] in Veterans and Service Members with Chronic TBI) and coordinating with other longitudinal studies (Chronic Effects of Neurotrauma (CENC), 15-Year Study). Successful strategies and challenges of enrollment and follow-up longitudinal monitoring of the chronic effects of TBI will be described.